Present and Obscured

Clarke, Harriet

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Present and Obscured: Disabled Women as Mothers in Social Policy

Harriet Clarke

INTRODUCTION

Maternal disability is a topic which figures only rarely in motherhood studies, and disabled mothers have only had intermittent presence in social policy research and social policy-making in the UK. When disabled mothers are recognized within social policy, their representation – both as women and as mothers – is often partial. This is problematic, not least as social policy shapes family life for all adults and children: it determines the availability and form of social security and services, shapes how assistance, within families and from without, is organized, and has wider impacts on life-course experience in relation to family formation, including having children, and labour market participation. This chapter constitutes a critical review of late twentieth- and early twenty-first-century social policy literature pertaining to disabled mothers: as well as identifying shortcomings in 'parenting' approaches where gender is not fully integral to analysis, it seeks to contribute to debates in motherhood studies on how disabled and non-disabled motherhood is framed within, and shaped by, social policy.

It is important to stress that disabled women have been fundamental to ensuring disabled mothers' increased social representation; yet the process of policy development, including the role of research development and academic writing, can contribute to an obscuring of how motherhood is experienced in disabled women's lives. My starting point is that users and producers of research – and other forms of expression comprising knowledge, experience,

and narrative – have a relationship to disability, as these social products have cultural and social consequences for mothers and others, an issue neatly summed up by Morris:

> Non-disabled people have had, and largely continue to have, 'absolute power' over narrative when it comes to the representation of impairment in literature, film, television, art. In my own field of social policy research, non-disabled people continue to set the research agendas and analysis of our reality (although things are changing and we have some good allies). (2001: 6)

Whilst concerned with 'disabled mothers', this chapter is not seeking to present fixed categories of womanhood, motherhood, or disability, but aims to address the ways in which disabled motherhood has been 'marked out' within recent and contemporary writing – whether to problematize women and mothering, to make women's experience visible, or to consider how best to ensure disabled women as mothers are recognized and, where appropriate, supported. Following an account of disability definition as a crucial historical and current politics, the ways in which disabled mothers are made visible are reviewed to assess both recent and current representations within policy debate and how future social policy and motherhood studies can engage more fully with the gendered impacts of policy on disabled women.

DEFINING DISABILITY

The challenge of definition in relation to disability as a 'category' – namely, who is a 'disabled mother'? – does need to be addressed. Roots of definition can be both personal – concerning self-definition – and public – through policy development and implementation, within public representation – with both personal and public forms of definition and

(re)presentation having influence on one another. Representations and analyses of disability alter over time, and depend on a wide range of factors in any given context. Factors can include impairment (or chronic ill-health) visibility, impairment impact or salience, extent of medical or administrative 'sanctioning' of 'disability' status – for example undisputed forms of diagnosis or access to policy provisions – and consideration given to social processes of marginalization.

It is consideration of social (including literary) processes of marginalization and analytical (including political) responses to them that is most fundamental here. Disabled people's influence on disability definition in the British social policy context was significant in the second half of the twentieth century and continues to be so today. Disability activism in the UK has made private experiences public through challenges to 'care and control' (i.e. 'care' which restricts rather than supports independent living). Building on the work of activists in the 1960s, disabled people organized and analysed the 'problem' of disability with a landmark contribution made by the Union of Physically Impaired against Segregation (UPIAS 1976): UPIAS distinguished between impairment – a characteristic of the individual person – and disability – socially imposed disadvantage operating through material, economic, and attitudinal barriers. This was at a time when social policies resulted in many disabled people living in institutions or facing poverty and isolation in their homes in the community (Barnes 2012). This 'social model' has been developed and debated over the past four decades but, from the moment of its inception, has provided a lens facilitating the assertion of disability as a form of social oppression. One significant form of oppression, which immediately points out how disability experience is gendered, has been in relation to reproductive rights which can be linked to earlier powerful discourses such as eugenics (Sayce and Perkins 2004).

The latter part of the twentieth century, then, provided 'new light' on the shared experiences of oppression for people living with impairment, including chronic health difficulties such as mental distress. Existing literature on the experiences of disabled parents is heterogeneous but was in strong part invigorated by wider disability analyses and activism: importantly it contains the contributions of disabled people – often mothers – in challenging social exclusions, including to from reproductive and family life rights. The focus in this chapter is primarily to review critically work developed in the UK context, influenced by the disabled people's movement and the 'social model' of disability. In referring to 'disabled people', I am including people living with impairment or long-term health concerns who experience exclusion, asserting my focus on social barriers and opportunities and access to self-determination rather than impairment experience: this focus is required as social science and policy discourse and practices can both contribute to marginalization and social control and seek to ameliorate it.

This chapter demonstrates that, while work has been produced that has explicitly engaged with disabled parents' experiences, in more, or often less gendered ways, the 'absences' are still frequent and notable, even in valuable contributions to motherhood studies. This can be seen both in British studies of motherhood such as the work of Gillies (2006), whose analysis of working class mothers has relevance to some disabled women, and in international historical analysis of 'maternalism(s)' as ideologies concerning women as mothers in social policy (Koven and Michel 1993; van der Klein et al 2012).

DISABLED MOTHERS EMERGING FROM THE MARGINS

Disabled mothers, indeed disabled parents, have often been either absent or marginal in sociological and social-policy writing on parenting. Thomas (1997: 63) identifies that disabled women's voices have been 'almost totally absent in sociological work on reproduction and parenting' but that 'there is a small but growing literature on disabled women's motherhood experiences springing from the disability movement itself'. Similarly Olsen and Clarke (2003: 5) highlight that 'conventional social policy research and analysis has been almost universally blind to the existence of disabled parents', and this reflects a failure to challenge the categorization of disabled people as 'dependent' and 'passive' rather than as providers of care including mothering and fathering (see also Wates 1997).

In related disciplines, there may be 'glimpses' of presence, albeit utilising different language, and it is usually the childhood experience of disabled parenting that is stressed. For example, Davis (2012) provides a historical analysis of motherhood experience from 1945 to 2000 where 'disability' rarely features. However, two women's own childhood experiences of 'ill' parents are reported to highlight implications for family division of labour and learning of domestic skills within the home. In social policy, disabled parents, and other disabled people, are often marginal in work focused instead on families with children who provide support for disabled, or 'ill', relatives. This research literature emerged in the early 1990s (Aldridge and Becker 1993) and, despite being seen initially by some as a 'flurry of interest' (Sheldon 1999: 652), has continued to expand in terms of both publications and influence; in policy terms this work helped to establish the category of 'young carers', as young people with this experience are now known in the UK, and increasingly internationally.

Just at the time when the social model of disability had helped to unify people whose shared experience had been previously fragmented by reference to different impairments, the

identification of ‘young carers’ as a specific welfare category provided impetus for critical disability perspectives on *disabled parents* to be asserted within academic journals. This came both from disabled women (Keith and Morris 1995; Morris 1997), following personal accounts of the experience of disability and motherhood in other writing (for example, Morris 1992), and from others who shared their concern with the lack of visibility of, and appropriate support for, disabled people as parents (Parker and Olsen 1995; Olsen 1996; Olsen and Parker 1997). Disabled women’s contributions were particularly vital as, although disabled women had a strong presence in the disability movement, there was an identified need to have disabled women better represented in academic disability research and feminist work (Sheldon 1999). The emerging debate on disabled parents and young carers concerned the risks of obscuring the lack of appropriate support for parents in their own right: this has produced valuable dialogue (Aldridge and Wates 2005) and integration (Clarke and O’Dell 2013), although overall there continues to be a significant schism between work concerning carers and disability rights. This reflects broader long-standing debate between some feminist writers who put forward the previously unrecognized work of care and those challenging the appropriateness of care-oriented social policy. The issue of women as carers has been a significant theme within feminist social policy, highlighting policy-shaped gender divisions of labour (for example Finch 1984; Dalley 1988; Pascall 1997). The term is critiqued, as care can place disabled people in a role of dependency rather than recognizing their relationships and roles, including mothering, interdependency between family members, and the importance of rights to choice and control (Morris 1991; Keith 1992; Morris 1996; Morris 2001).

A further context for the development of literature on disabled parents was set by government, where *parents* began to receive more attention than previously when the policy

focus had been on child-protection. Support for parents was recognized as the other side of the coin of child welfare – 'prevention', 'parenting capacity', and 'parenting programmes' became part of the policy lexicon. This predated the first Blair government but was a key feature of it, and led to a growth in parenting-oriented research[1]. Whilst parenting was moved closer to the centre-stage of policy, gender was largely missing. Studies concerning disabled parents have predominantly focused on disabled mothers, yet this has led more strongly to recognition that fathers are underrepresented (Morris and Wates 2006; Kilkey and Clarke 2010) rather than to a gendered analysis of disabled motherhood. This lack of attention to gender was reflected in other fields of policy: for instance, workers and 'work-life balance' and the related issue of unpaid family carers were clearly gendered issues but presented in predominantly gender-neutral terms.

Part of the challenge for this developing literature on disabled parents was to assert the importance of adults' services for parents – often mothers – which enable parental choice and control in family life. Whilst this was a predominant concern of policy makers, a broader challenge was to identify the economic and social marginalization faced by many disabled parents and their families, including in relation to gender, single parent families, ethnicity, class, and poverty. For example, Morris (1996: 6-7) highlights that, as children with single mothers are more often identified as 'young carers', '[i]t is particularly disappointing that feminists have failed to highlight the way the "young carers" debate is part of the general attack on single mothers, which has been such an important part of the political landscape of the 1990s'. Jones et al. (2002: 6), who undertook research with black young carers and disabled or ill family members (usually mothers), asserted that impairment and disability are 'shaped by gender, class, and specific expectations based on notions of difference that are

[1] For example, the Department of Health's 'Supporting Parenting' initiative in the late 1990s, which funded Olsen and Clarke's (2003) study on disabled parents.

themselves influenced by cultural, social and economic factors'. This required consideration to be given to the impacts of racist, disablist, and sexist oppressions experienced by those in families which include young people with care responsibilities. Not only does this point to the importance of understanding the range of structural impacts on the lives of disabled mothers, it signals the importance of considering all motherhood in social context, to include that of social policy.

BECOMING A MOTHER?

Motherhood of course concerns women's relationship to childbearing and childrearing: however, not all mothers bear their children, not all childrearing is conducted by those who bore the child, and *not* bearing and/or rearing children is itself understood with reference to an ideal of motherhood which involves both producing and caring for children (see Letherby 1999). Recognizing the diversity of all women's experience in relation to motherhood is crucial for engaging with disabled women's experiences of it. Research with disabled women including disabled mothers shows that participating in motherhood is still strongly valued by most women:

> In highly industrialized societies today, childbearing is an option not an inevitability for most women. An increasing proportion of women in Britain do not give birth to children, and many are 'child-free' through choice. However, the majority of women do have at least one child, and for most the experience of bearing and/or rearing children is something they would not want to forego. (Thomas 1997: 622)

As indicated above, the shared focus of the writing produced during and since the later part of the twentieth century maps directly onto a period of social change for disabled people, as a

result of the emergent disability rights movement and challenges to care-focused policy. Whilst autonomy and personal control over support have been sought, the particular circumstances of disabled women may create conflicts concerning reproductive and mothering 'choices': limited delivery of personal assistance or care – or indeed no assistance despite support requirements – and the difficulty of accessing rights to full participation in the private and public sphere affect women as potential or current mothers. As Reinikainen (2008) argues, where the idea of the private sphere as the 'natural' place for both disabled people and for women is upheld, this can be extremely restrictive in that the home becomes the presumed environment for disabled women. This is dissonant when present alongside negative presumptions concerning disabled women's appropriateness as mothers.

Reproductive risk discourse (for example, concerning hereditary 'risk' to a child or potential impacts of motherhood on the wellbeing of a disabled woman) is a particularly strong conduit of messages about appropriateness for bearing and/or raising children. Thomas (1997) spoke to disabled women in England who reported on reproductive risk discourse they encountered from health professionals and family members which could communicate that risk, and so motherhood, ought to be avoided. Disabled women themselves could share in these concerns and, in this context, 'decisions are made not to have a child/another child, or to be sterilized, or to terminate a pregnancy' (Thomas 1997: 633). Where family members, including disabled women's own mothers, are also concerned with risk, there is an intergenerational aspect which might result in disabling practices. Given intergenerational and family-relational aspects of disability, 'disability studies and the sociology of disability have a lot to learn from non-disabled people's experiences of disability' (Rogers 2010: 68), particularly if we are to understand and change disabling pressures (re)produced by people in their private family lives.

Whilst each generation may experience reproductive risk discourse differently, becoming a mother despite its presence can be reported as a success against others' disabling expectations (Olsen and Clarke 2003). Similarly, from her research with disabled women, Thomas also reported that for many women 'their personal fight in the face of disablism was fundamentally *about the right* to be mothers and homemakers' (Thomas 1997: 639). Private 'decisions', at times in restricted circumstances, which lead to 'absences' – no children or no further children – are an aspect of disability and motherhood which are not easily made visible, although non-motherhood in the UK is addressed elsewhere (for example Letherby 1999). Given specific messages concerning reproductive risk, wider messages concerning disabled women as 'risky mothers', and the importance of motherhood to many women's experience of themselves as women (whether or not they are mothers), there are concerns that feminist calls for rights not to bear children have failed to look at the exclusions and restrictions impacting on some disabled women seeking to become mothers or feeling not able to contemplate it:

> Reproductive rights must not be seen solely as the right not to bear children. This is a trap that the women's movement has fallen into in the past, probably because of its failure to look beyond the immediate experiences of a particular, privileged group of women. Reproductive freedom must include the right for women to bear children should they wish, whatever their impairment, ethnicity, sexuality or class, otherwise it can become a demand which implicitly condones eugenics. (Sheldon 1999: 651)

If disabled women have children, or non-disabled mothers become disabled or chronically ill, their experience as mothers is often obscured in policy research and debate.

OBSCURING THE MOTHERING ROLE

The literature on care has often degendered the recipient of care whilst highlighting the gendered nature of care as reproductive work (Meekosha 1998). This was exacerbated by the government's focus on parenting in their commissioning of research, and in policy development, implementation, and regulation. A strong example is the work of social services' regulators: the Social Services Inspectorate report 'A Jigsaw of Services' (Goodinge 2000) and the later Commission for Social Care Inspection report (CSCI 2009) sought to stress the relevance of gender so far as recognizing services' need to respond to parents – both mothers and fathers – though this was in part obscured by the predominance of parenting language in each publication. Goodinge (2000: 11) reported that lone motherhood was one factor impacting on disabled mothers' increased visibility with services; however, gendered experiences of disability and family life were not the focus and gender was considered to be of importance principally as one aspect of equal opportunities: 'The SSD aims to meet the needs of disabled adults in their parenting role in respect of race, religion, language, culture, sexuality, gender and disability'. In CSCI (2009) the commissioners' language (of parenting) was reflected back in the talk of both family members and professionals, as captured in the words of a disabled mother: 'A lot of the problems we face are because there is a perceived contradiction between being a parent and being disabled, as if you can't actually be both. [...] It's the perceived contradiction between being a disabled person and being a parent' (Disabled Mother, CSCI 2009: 21).

This excerpt illustrates that when seeking to assess the extent to which disabled mothers and fathers consider themselves visible, as researchers we can produce findings which remove key elements from those accounts and so 'lose' the mothering role.

‘LOSING THE MOTHERING ROLE’

The actual loss of role, rather than the lack or obscuring of representation, is also featured in the literature. For example, the implications of a ‘dependency’ model, focused on functional care, and obliterating reproductive roles for disabled women, is illustrated clearly through the personal experience and expert policy-research knowledge of Morris (2014), where she contrasts this with a policy focus on rights to independent living. She recalls another woman, like her, called Jenny, and, like her, a single parent at the time they were on a spinal unit together in the 1980s; unlike Morris ‘the other Jenny’ had support requirements which were not met in a way that would allow her to continue living with her child:

> she realized that there was no other option open to her than to enter residential care and to relinquish custody of her daughter to her ex-husband. …. By 2008, we had an Independent Living Strategy, supported by all political parties …. [s]ignificantly, this Strategy included a section on disabled parents because – as a result of earlier research and campaigning – it was finally being recognised that disabled people should receive practical support to enable them to be parents like anyone else. Maybe someone like ‘the other Jenny’ would not have lost her child and her chance of returning to an ‘ordinary life’ if she had become paralysed 20 years later. (Morris 2014)

For disabled women who have become parents but face battles in accessing support for themselves, in their own right, there can be a concern that they are not going to be taken seriously as a competent loving mother. Cherry’s account of a disabled woman’s experience reflects those of women reported in other research literature (for example, Olsen and Clarke

2003) for whom accessing support was difficult and could be viewed as potentially risky for the family unit:

> In February 2008, Ms A, a dedicated and loving mother of two small children, contacted social services for help with extra care for her youngest child and for taking and picking up her other child from school as her disability had worsened. … Ms A recalls 'It feels like social services were waiting for me to fail so they could accuse me of being a bad mother. My fears were borne out when I heard that a new social worker wanted to investigate "how [my] condition affected [my] day-to-day ability to look after the children" and the Family Support Worker raised [the idea] that my children could be fostered'. (Cherry 2009: 10-11)

Much has also been reported on the impact of inappropriate assistance whereby control over aspects of family life is felt to be taken away. Whilst this can be presented in terms of functional 'tasks' – the provision of food, support to take a child to school – such support may be experienced as only being provided when women meet disabling expectations such as demonstrating 'dependency' and accepting that professionals and non-disabled people 'know best' what is needed (Thomas 1997).

Olsen and Clarke (2003) reported that, for women who were not in paid work nor engaged in other activities outside the home, importance could be attached to how disability, which excludes them from work, also enabled them to be full-time mothers. Others undermining the value of this might be felt particularly acutely. For example, a disabled mother with a physical impairment living in a two-parent household felt that her own impairment provided a 'camaraderie' with her disabled child; however she relayed that a professional felt she was

a negative influence on her child, with the child considered to be 'emulating' her as a disabled woman. A disabled woman's impairment was therefore equated with risk, rather than one feature amongst many which can be positive in a parent-child relationship.

PRESENTING MOTHERHOOD

Just as disabled women themselves can be aware of, and sometimes subscribe to, reproductive risk and wider risk discourse, studies in sociology and social policy have also identified the risk discourse in relation to raising children, particularly the notion, central to it, of 'good enough' mothering – or the emptied-of-gender 'good enough parenting'. This can have implications for the presentation of self and the conduct of parenting and family work, when a fear of losing the right to care for children requires significant efforts to demonstrate the quality of mothering. Thomas (1997: 636) found that 'disabled women really do feel under surveillance, and that feeling is usually well founded because disabled women are often assumed by professionals and lay people (sometimes close relatives) to be incapable unless they can prove otherwise'. Some disabled women may also feel judged in relation to whether or not a child is engaged in their support: the 'young carer' category, which was initially developed through social policy research, has later been reproduced in policy and practice through the delivery of 'young carer' services and awards. Whilst 'young carer' has a public currency and can provide both a route into support and a language for discussing experience within the family, this categorization may for some disabled mothers – and fathers in Olsen and Clarke's 2003 study – be something to avoid: 'I would rather have grass six foot in the air, than have people think I am getting my kids to do too much' (Mother, physical impairment and mental distress in two-parent household, in Olsen and Clarke 2003: 87).

Such findings of managing self-presentation in response to particular representations of disability and motherhood are not restricted to the UK In the Canadian context, for example, Malacrida (2009: 113) found that disabled mothers with a range of impairments were responding to the impossible 'ideal motherhood' faced by all women, but that for them this could require 'enhanced maternal performance', demanding exceptional effort. Women desired 'recognition as women entitled to be mothers' and 'creatively used normative aspects of ideal mothering to stake their claim to both motherhood and femininity'. Visibility (and opportunities to access appropriate support) are thus reduced as disabled women avoid seeking recognition, or avoid 'intervention', for fear of disablist responses, aware as they are that being seen to achieve in motherhood can, as in the case of non-disabled women, provide access to social acceptance as adult women.

CONCLUSION

The development of the 'social model' approach to disability in the UK, enabling a critical perspective on the disabling influence of policy and role of professional experts, has led to the emergence of writing and campaigning concerning disabled parents; this has challenged work focused on the implications and outcomes of parental illness or impairment for children, rather than lack of appropriate support for parents. Disability and parenting have, separately and together, often been under-considered in relation to gender and therefore, over the past quarter of a century, whilst a broad literature base has developed concerning disabled parents, only some of this work has focused on motherhood. Parenting-orientated research has been under-analysed in relation to gender but has highlighted that disabled mothers may face specific obstacles around reproductive risk discourses, around being positioned as risky and/or dependent mothers, and around managing roles of work and care both of which can be impacted by disabling barriers and gendered expectations. In contrast to the largely

degendered parenting research, elsewhere, and particularly in histories of policy, the influence of motherhood on the development of welfare states has been examined through consideration of 'maternalism'. Maternalism can be understood as ideologies concerning women as mothers (Koven and Michel 1990) that may serve either feminist or more conservative political ends (van der Klein et al 2012). Disability is largely absent in maternalism-focused analysis, which provides further indication that future work should examine how disability, parenting, and gender are present in, and shaped by, social policy and consider how maternalist ideologies impact on disabled women, either directly (as recognized mothers) or indirectly, where motherhood is disassociated from disabled women.

Maternalism may most often be examined historically; however, policy recognition of, and responses to, disabled mothers are contemporary issues. Further, motherhood-focused research – which acknowledges how disability as a category is altered through policy to broaden or (as currently) to restrict access to support – is strongly required. Fewer women who have children will be recognized by services as experiencing disability as different policies re-draw 'who is a disabled person'. For example, Disability Living Allowance – which is for disability related living costs – is currently being replaced by Personal Independence Payment which is anticipated to bring savings to government due to changes in assessment (Roulstone 2015). Restricted access to social security and to services in a time of so-called austerity is intensified by the tendency for the 'vulnerability' of disabled people to be stressed in order for support to be accessed. As considered above, research to date suggests this is a significant concern, as disabled mothers can perceive risks in presenting as 'in need'. Moreover, requiring the presentation of dependency for support reduces confidence in services to enable rather than intervene.

The review presented here opens up the need to look beyond ‘disabled parenting’, as a disabled individual’s care-role, to motherhood as a life-course institution shaped by social policies, which may not be experienced positively, or at all, by women facing disability exclusions within private and public life. Whilst future social policy cannot be foreseen precisely, it is clear that analysis of the implications of the ways in which disabled women as mothers are represented in social policy will continue to require consideration of the ways in which disability is marginalized – and yet unsatisfactorily can be made a core marker of person-status and social position. Such work must also address how policy and policy debate is gendered – and can be unsatisfactorily de-gendered – and how disability and gender intersect across private and public lives over time. To advance disability and motherhood studies, building on previous feminist disability research and activism, alongside wider motherhood studies, is required. However, there is less funding available both for research and for the work of disability organizations. Urgent social and economic distress for some mothers, especially as a result of squeezed public resources, also potentially leaves less room to consider the gaps in analysis to date; for example, in relation to women who choose not to bring up their children or have that choice removed from them, in relation to disabled women who do not have children.

In developing future work on disabled mothers, the availability of funding, when disability, care, and parenting are often de-gendered in policy, may be but one barrier: there are very likely others which shape opportunities to advance disability and mothering research. At the end of the last century, it was said that, for disabled academic women, ‘it may be more appropriate to focus on gender or women’s studies, rather than the too often ungendered territory of disability studies’, especially if your work is framed by others in disabling terms as the ‘story of your personal tragedy’ (Meekosha 1998: 166). Such pressures may have

changed but they cannot be assumed to have been removed, and Meekosha's analysis points to the importance of considering research fields and disciplines as territories which might be reshaped – albeit in challenging circumstances – to develop further feminist motherhood and disability research in order to inform social policy.

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